



Pulmonary Hypertension Association

Empowered by hope

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Dear Chairmen and Ranking Members,

I write you today on behalf of the Pulmonary Hypertension Association (PHA) to ask for your support of the public health goals of the *Kids First Research Act* (H.R. 2019). Please work to advance this legislation through the legislative process so that its provisions establishing a new pediatric research initiative at the National Institutes of Health (NIH) might be enacted.

The pulmonary hypertension (PH) community understands the value of investing in critical pediatric medical research. PH is a disabling and often fatal progressive condition where the blood pressure in the lungs rises to dangerously high levels. In PH patients, blood flow between the heart and lungs is blocked or constricted. As a result, the heart must pump harder causing it to enlarge and ultimately fail. PH can be idiopathic, and occur without a known cause, or be secondary to other conditions, such as, scleroderma, lupus, blood clots, and sickle cell. PH impacts individuals of all races and ages, including children. Similar to other disease states, pediatric research into PH lags behind adult research. While there are nine FDA-approved treatments available for adults with PH, none are approved for children.

PHA supports a pediatric research program to improve the lives of children impacted by PH and we are pleased that Congress is interested in supporting pediatric research at NIH. In the interest of improving care for PH patients, PHA also engages in advocacy activity, including advocating for the *Pulmonary Hypertension Research and Diagnosis Act* (H.R. 2073), budget neutral legislation designed to improve diagnosis of PH before the condition reaches an advanced stage. We hope you will continue to support and advance legislative efforts focused on bolstering research activities and improving care for patients with PH, such as H.R. 2019 and H.R. 2073.

Sincerely,

Rino Aldrighetti
President & CEO

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